

TO THE HEALTH POLICY COMMITTEE REGARDING HB 5036

09/13/2018

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Representative LaTanya Garrett

Representative Kevin Hertel

Representative Julie Calley

Representative Bronna Kahle

Representative Sheldon Neeley

Dear Chair Vaupel and honorable members of the Health Policy Committee,

My name is Joel Troyer and I am from Bronson, MI. My wife, Anna and I are the proud parents of three beautiful children, Landry, Cora and Audra who are ages 5, 4 and 1 respectively.

When our firstborn and only son, Landry was born on January 8th, 2013, it was the proudest day of our lives. He was born healthy and strong and was everything we imagined he'd be. When you sit and hold that child for the first time so many hopes and dreams for them flood your mind. We were envisioning little league games and teaching him how to field short hops in the back yard. we envisioned teaching him to bait his hook and landing his first fish. We envisioned the childhood our fathers gave us.

Early on, Landry was developing normally, and every check-up brought good news. We were vaccinating Landry according the CDC schedule, and we did notice that he was developing eczema and seemed to be sick quite often, but he continued to hit all his developmental milestones. He was crawling and walking by 10 months and by 1 -2 years he'd developed a 50 - word vocabulary. He loved his grandma and sitting on her lap being read to. He was counting to 3 and saying some of his ABC's. He'd point and laugh at the dog, and I vividly remember every afternoon when I'd come home from work, he was standing in the window waiting on me because he heard my truck coming down the road. He was always the first to greet me. Everything was as it should be.

Then in his second year we noticed some changes. He stopped developing new words. We wondered and asked other parents what could be causing this, and we were always given the same answer, "He's fine. They all develop at their own pace". Even his pediatrician thought nothing of it, so we continued with the CDC vaccine schedule. He became a hyper child and was nearly uncontrollable. We had difficulty going places because he was so out of control. He also stopped sleeping through the night. He'd wake up nearly every night at around 2-3 AM and would literally be jumping in his bed, laughing uncontrollably. We would take him to our living room and rock him, usually until around 7 AM when he'd finally fall asleep, while we had to begin our day on no sleep. These were ALL serious warning signs of much deeper underlying issues with his immune system. We simply didn't know.....and neither did anyone else.

In November of 2015 the severe onset began. It was basically overnight that he stopped looking at us, began chewing on everything (including himself), rocking back and forth, pacing in a circle for 45 minutes at a time, having small seizures, severe separation anxiety, loss of appetite, sensory and motor dysfunction, and he completely stopped responding to his name. All language he had was completely gone. We were completely devastated. We searched and searched online and the only answer that came up was "Autism".

HOW could a completely normal and healthy child go from normal to a severe and debilitating developmental disability almost overnight? We asked his pediatrician and he checked for tumors on the brain. When that was negative his advice (and effort) disappeared. He simply shrugged his shoulders and said, "That's just how autism happens". Quite frankly, the worst answer to any question we've ever asked a doctor. We checked his hearing and it came back normal. We could not find a reason why this had happened. We were in a state of mourning and grieving at that time. Our son had disappeared before our very eyes and he'd become a shell of his former self.

Because the pediatrician's answer didn't make sense to us, we began our fight. We found a doctor in Los Angeles, CA who treated Immune Dysfunction (NIDS) and immediately flew to L.A. to start treatments. We inundated ourselves with knowledge and learning that continues to this day. Our suspicions that Landry was injured through the CDC vaccine schedule were confirmed. The onslaught of vaccines was far too much for his little body to bear, and he was having issues detoxing the toxins and metals. His ANA titers were 1:640 (the highest possible reading) and he had retroviruses along with severe GI issues and candida overgrowth. We discovered that his immune system was attacking itself. Upon further testing through the Cunningham Panel of Tests (Not covered by insurance), we discovered Landry has what's known as PANS, or Pediatric Acute Onset Neuropsychiatric Syndrome. To discover this illness had a name was a source of relief for us. We also discovered just how many children have this who are going undiagnosed. Sadly, if our pediatrician would have simply recognized these symptoms immediately, our entire family could have been spared so much frustration and pain.

Our treatment consisted of going gluten and dairy free as well as no nuts, whole grains or red or blue colors. In an effort to avoid toxins we have gone completely organic and no longer vaccinate. Landry takes anti-viral medications as well as anti-fungals to control candida. He takes supplements to help his body maintain crucial vitamins and minerals and a slew of other meds to help deal with mitochondrial dysfunction, IgG deficiencies, autoimmune encephalitis and other issues involving his GI system. We eventually tried several different therapies including going to Panama City, Panama to do umbilical cord blood stem cells. Needless to say, the costs of doing this are astronomical. We have done MNRI Training and therapy as well as hired a speech therapist for him. Landry has improved tremendously over the

course of the last 2 years. We have "calmed" his immune system and he is doing much better. While his receptive language skills have greatly improved (we thought he was deaf and now he's our best listener), his expressive language still has a long way to go. He will allow us to read to him on occasion and his direction following and general cognition are much better than they were when he regressed. He's happy and playful again, but he's still far behind his peers socially. He makes wonderful eye contact now and even though we believe he's on the path to recovery, it's still very difficult to watch your almost 2 - year old begin passing your 5 - year old in many different developmental areas. As a parent, this is not a gift. This is not a blessing nor is it a different way of learning. This is an illness. This is frustrating for us and for Landry. He KNOWS he's behind, and we tell him every single day that none of this is his fault. He is very sick, and Mommy and Daddy are working tirelessly to make him better. No matter if it breaks us financially.

We eventually found a new doctor closer to home named Dr James Neuenschwander in Ann Arbor, MI. Dr Neu has tried several different treatment methods including MB12 injections and a few others. Since Landry hasn't responded to those we are going to have to look at getting IVIG for him after some more testing. His words to us regarding IVIG were, "Good luck in the state of Michigan". You can imagine our frustration at the lack of support from the medical community and insurance companies for treatments that are so desperately needed for our kids. But we've moved heaven and earth for Landry, and we will continue to do so.

And that is why Rep. Aaron Miller and others have sponsored this bill. It's because he understood we were speaking on behalf of our son. We are the voice that was stolen from him by PANS and the vaccine schedule that caused it. Landry may have lost his ability to speak, but his testimony is reaching other parents and helping other kids from coast to coast and even across oceans. Because we are speaking out, other kids are getting the help they need and overcoming this devastating illness. If Landry can give knowledge and understanding to other parents, why can't his story give knowledge and understanding to pediatricians who are in a position to stop this madness before it truly begins?

To those reading this letter, we need you. Our son needs you. We are at a crossroads not only in MI, but nationwide. We believe healing and recovery is possible. We have watched our son slowly recover from this, and we do believe God has a powerful and ordained plan for Landry's life as well as so many other children across this great State. We must follow the steps of Illinois and Delaware and demand better for our children by giving them the opportunity to seek whatever treatments are needed for their recovery.

The time to act is now.

Sincerely,

Joel & Anna Troyer

Bronson, MI.

Luke 3:5

